



Sarcoma Patients EuroNet

Preamble

***“We have spoken European.
It is a new language which one will have to learn.”***
Aristide Briand, (1862-1932), French politician, Nobel Peace Prize 1926

***“Only when Europe speaks one language and combines its strengths,
will it be able to make a mark.”***
Helmut Kohl, (*03.04.1930), German politician, 6th Federal Chancellor

***“Tumours classified as rare cause 20% of all cancers.
Challenge 1: Rare cancers are not known or hardly known – therefore there is often no publicity,
no lobby and little financial assistance.
Challenge 2: Patients with such diseases often stumble through the health care systems of their
countries in search for information, medical expertise, quality treatment, therapy options and
clinical studies.
Challenge 3: There still are scores of countries in Europe in which the costs of recognised
tumour therapies, even for rare tumours, is not covered by the health care systems.”***
ESMO Conference on “Rare Tumours in Europe, 6th of November 2008 Brussels

***“Rare cancers, including all cancers affecting children, are widely spread across Europe and
represent 20% of all cancers. Each year, more than 440,000 Europeans develop a type of rare
cancer. In addition to facing a devastating and life-threatening disease, these patients are
challenged by a number of specific hurdles because their type of cancer is rare. In Europe, patient’s
access to care for rare cancers is still inadequate and survival rates differ significantly across the
EU.”***
Press release 12th of Dec. 2008 by ESMO (European Society for Medical Oncology)

***“I was diagnosed with a rare cancer 10 years ago. When you are in this situation time is of the
essence. The struggle to get a correct diagnosis, to find the right specialist and to have access to
the best available treatment is a great challenge for a person who already feels that there is no time
left.”***
Sandy Craine, Spokesperson for patient group in England with patients suffering from CML (Chronic
Myeloid Leukaemia).

***“Sarcoma Patients EuroNet is a very welcome development. We need to involve patients in clinical
trials at the design stage so that the relevance of what we do can be considered at the outset. In
addition SPAEN will be valuable helping patients understand what being treated in a clinical trial
could mean to them. Together we can complete research more quickly and introduce new
treatments faster.”***
Prof. Jean-Yves Blay, Claude Berard/Lyon University, Chairperson of CONTICANET.EUU and the EORTC
Sarcoma Group

“Nothing about us, without us!” ECPC - The European Cancer Patient Coalition

***“In Europe every sarcoma patient will know that they can reach out for information, support and
advice from other patients and from patient-led expert organisations which can understand and
address their needs.”***
Vision - Sarcoma Patients EuroNet Assoc.

Statutes of Sarcoma Patients EuroNet Assoc.

§ 1 Name, Office, Calendar Year And Language

The association is known as "Sarcoma Patients EuroNet". It has to be registered in the Friedberg/Hessen/Germany register of associations (Registergericht) and will include Assoc. = association as a suffix to its name after the registration.

Following should be used as annotative addition to the name (for logo / wordmark / trademark) in the corresponding language of the member country:

“The International Network of Sarcoma Patient Advocacy Groups”

The association has its office in Wölfersheim/Hessen/Germany. The place of execution and jurisdiction is Wölfersheim. The business year of the association is the calendar year.

These statutes, future amendments, meeting minutes and any written communication with the German Register Court (Registergericht) and German financial authorities must be formulated and documented in German. The general communication within the association will take place in English.

§ 2 Objective Of The Association

1. The association's objective is the promotion and exchange of information about community health care at an international level amongst the members, who then in turn promote community health care amongst the general public.

The association performs the function of an umbrella association for its members in a vital area of health care – the area of cancer and sarcoma.

Main objectives here are,

- to increase knowledge about sarcoma,
- to create a better awareness about sarcoma,
- to integrate the patients' perspective and needs into sarcoma research,
- to improve the situation of sarcoma patients and their families internationally through the availability of information developed by the co-operation of the members of the association and from authoritative sources outside.

2. The following principles govern the functions of the association, cooperation of the members and methods for achieving the association's objective:

- A. The association will be exclusively led by sarcoma patients or patient representatives.
- B. Sarcoma Patients EuroNet (SPAEN) projects and activities are supported by the members as SPAEN/international projects, not as national projects or activities, although in a national programme of work they may be presented as joint activity while using the SPAEN branding and house-style.
- C. The interest of the collective indication 'sarcoma' takes precedence over interests regarding individual sarcoma sub-types.

3. "Sarcoma Patients EuroNet" strives to make available information about diagnosis, treatment

and care of people who live with sarcoma, and support for their partners and families.

4. The association's objective will be met with the help of the following activities:

- Formation, operation and maintenance of multilingual websites,
- Conception, planning and implementation of events/trainings/webinars for the members and other interested dialog groups,
- Exchange, development and realisation of various other projects and information and communication activities which help in achieving the association's objectives.
- Building partnerships with the members to share knowledge and experience.
- Providing current, reliable and understandable material with information about diagnosis, treatment, care and support of sarcoma patients and their loved ones.
- Building cooperation with medical specialists who treat sarcoma and carry out sarcoma research studies. This is important for sharing information, developing mutual understanding and enabling patients to benefit from clinical studies and the support of experts.
- Encourage sarcoma patients internationally to form sarcoma patient support groups, especially where there are none yet.
- Building support for the sarcoma cause from European and other international health care policy makers, given that it is applicable to the purpose; this also involves for instance, learning and utilizing the best practical experiences at a national level, where available.
- Increasing awareness about the 'forgotten cancer - sarcoma' in the international society.- Early integration of experienced patient advocates to consider and incorporate patients' perspective and needs into the conception of clinical research/trials,

5. The association can also carry out other measures; for instance, renting/ purchasing of infrastructure or founding of or participating in a company, if it helps in achieving its objectives.

6. The association will be run according to democratic principles and is not bound nationally, politically or denominationally. (With the Exception: Statutes, association registry and finances are subject to German law.)

7. The property of the association must be used only to meet its statutory objectives.

§ 3 Memberships

Members of the association can be native people or organisations who support the objectives of the association.

Types of membership:

1. The association has **full members** who have one voting right per organisation in the General Meeting. These organisations will be identifiable organisations who may or may not be legally incorporated according to their country's laws. An individual person can be a full member on an interim basis under the condition that he/she has actively planned, prepared or already begun founding a sarcoma patient group.

2. The association has **corporate members**. These can be commercial enterprises, companies or other organisations, that would like support the association financially (long-term sustaining partners). Corporate members don't have voting rights at the General Meeting. The Board organises a yearly meeting with these specific members to inform them about the development of the association.

The Board of the association has to develop and publish directives and guidelines to regulate the cooperation with corporate members.

Main principles are:

- Neutrality of the association – no exercise of influence from third parties
- Focus on patient needs
- Transparency and disclosure

3. The association has **supporters** without voting right in the General Meeting. These members can be individual medical specialists, treatment centres, clinics, research facilities, expert networks, and professional associations etc. who support the association ideationally or with cooperative projects.

4. All requests for memberships must be made in writing. The application must be addressed to the association's Board of Directors, which will decide on acceptance of the application. Refusal by the Board of Directors is not subject to appeal. There is no obligation for acceptance of any application by the Directors of the association.

§ 4 Termination Of Membership

1. The membership of any class of member can end by way of:

- Withdrawal from the association,
- Deletion from the member list,
- Debarment,
- Death of member,
- Dissolution of the member organisation.

2. Withdrawal will take place following a written declaration to the Board of Directors. It is permissible only at the end of a calendar year with a notice of 3 months.

3. The deletion of membership takes place if two consecutive annual fees of a member are in arrears and these arrears have not been fully deposited within one month of sending a written reminder. The reminder must be sent to the address of the member last known to the association. A delivery confirmation is not necessary. The reminder must inform about the imminent deletion. The reminder is considered effective even if the communiqué comes back undelivered. The Board of Directors will take the final decision on the deletion of the membership. The deletion will be informed to the concerned member.

4. Debarment from the association is permissible only if there is an important reason. Such a reason can be if

- the member has seriously breached the interest of the association,
- the member has breached the statutes on several occasions.

5. The Board of Directors will decide upon debarment. The Board must inform the concerned member in writing at least two weeks before the decision on debarment is taken and invite the member to respond within a stated reasonable time limit. Till the time the Board of Directors take a decision, the member may comment on the intended debarment in writing or verbally. The debarment will be effective once the decision is taken. The Board of Directors should inform the member about the debarment in writing if he/she was not present during the proceedings.

§ 5 Organs Of The Association

Organs of the association are:

- The General Meeting
- The Board of Directors. It consists of an elected part and – if applicable – of an expanded/consulting part.

§ 6 The General Meeting

1. The General Meeting is responsible for following affairs:

- Approval of budget presented by the Board of Directors for the business year, accepting the annual report by the Board of Directors, discussing the reports with the Board of Directors, approving the Board of Directors for the last financial year
- Fixing the membership fees
- Election and dismissal of members of Board of Directors
- Deciding on amendments to the statutes and dissolution of the association.

2. The General Meeting is not public. The chairperson can permit guests. A quorum will be 3 full members (patient groups). Attendance by telephone or video conference is possible, needs to be requested by the particular member though.

3. One of the two chairpersons will chair the General Meeting; in his/her absence, another member of the Board of Directors will chair the meeting. During election, an election manager or election committee can be made responsible for the proceedings in duration of the election and preceding discussion.

4. The secretary prepares minutes of the meeting. The secretary and chairperson must sign this document. The minutes of General Meeting must include: Time and place of the meeting, name of chairperson and minutes writer, number of members present, number of members with voting rights, determination of proper calling and quorum of the meeting, agenda, applications received, votes (number of yes votes, no votes, abstentions, invalid votes), type of ballot (open or secret), applications for amendments to statutes and objectives, decisions

5. The Board of Directors must call the General Meeting in writing with a notice period of 6 weeks. The written invitation must include the agenda. A standard General Meeting has a quorum. If decisions need to be taken, they must be included in writing with the invitation. If amendments to the statutes need to be undertaken, the text in old and new version must be included. The notice of invitation begins with the day the invitation is sent to the address of the relevant member.

6. A decision on dissolution of the association must be taken with a two-thirds majority of participating members with voting power.

7. A decision on amendment to the statutes and amendment or addition to the association's objective must be taken with a two-thirds majority of participating members with voting power.

8. **Full members** have one voting right per organisation in the General Meeting. That means: All participants representing one organisation/full member must agree on one vote during the voting. A member may also participate in the General Meeting on telephone or through video conferencing with the permission of the chairperson. The decision is taken with a show of hands. A present member may request for a secret, written vote. The member taking part on telephone or videoconference will inform the chairperson publicly. The chairperson adds the vote accordingly in the vote result. The General Meeting takes decisions with the majority of the votes cast. Vote abstentions are not considered.

9. Following is applicable for elections: If in the first election no candidate has the simple majority of the submitted valid votes, a runoff vote between the two candidates with the highest votes takes place. If there is a draw, a second ballot takes place after a short discussion. Vote abstentions and written invalid votes are not considered.

10. The General Meeting should meet at least once in a calendar year. The Board of Directors can call other exceptional General Meetings if it deems them necessary. The Board of Directors must also call a General Meeting if a quarter of the registered full members request it in writing. Two auditors will check the association's financial affairs. The General Meeting will appoint these auditors for the duration of 3 years. Reappointment is permissible once. They must be able to audit the entire assets of the association any time. The audit will take place at least once a year (just before the General Meeting). The auditors will present their audit report in the General Meeting. On their request, the Board of Directors may be relieved of their duties.

11. For urgent amendments to the statutes, the Board of Directors will send a written ballot to the full members. In such a case, all full members will receive the same letter via post, comprising of:

Part A Correspondence – detailed discussion of the issue by the Board of Directors and/or any members requesting a change

Part B Old and new text of the statute passage to be amended

Part C Reply or voting form

The message should be sent at least 4 weeks before the date of reply or voting. This reply or voting date must be clearly highlighted in writing. Association will accept votes till the reply or voting date. The members can vote via post, fax or e-mail (scan the reply or voting form). The written amendment to the statutes is valid and is considered to be accepted if 2/3 of all reply / voting forms arrived in time are indicated with YES.

The Board of Directors is obliged to announce the result of the written ballot via e-mail and on the homepage of the association.

§ 7 The Elected Board Of Directors

1. Only full members can be elected by the General Meeting as members of the Board of Directors. A maximum of three Board Members from the same country can be elected to the Board.

2. If possible, the elected Board of Directors reflects the essential disease subgroups under the term of "Sarcomas", that are:

- GIST (Gastrointestinal Stromal Tumours)
- Soft Tissue Sarcomas / Tumours (incl. Desmoids)
- Bone Sarcomas / Cancer / Tumours (incl. Chordomas)

3. The elected Board of Directors consists of 7 persons, namely

- two equal Board Chairpersons with special functions/tasks
 - * one for - medical development/relations
 - * one for - organizational development/relations
- the financial director
- the secretary
- three members/assessors

4. Each Member of the elected Board of Directors is authorised to represent the association in legal, extra judicial capacity and to third parties (= the sole power of representation).

5. The elected Board will be commissioned for a duration of 4 years by decision of the General Meeting. It will be in office until the statutory commission of the next Board.

6. Inside the association: The association is sole represented by the two equal Chairpersons.

7. The office of a member of the Board of Directors ends with his/her retirement from the association. One person can only hold one office on the Board. In case a member withdraws from the Board of Directors during his/her office, a replacement member appointed by the organisation of the country to which the withdrawn member belonged will complete the remaining term. If a replacement member cannot be called, the office remains unoccupied till the next General Meeting and the functions of the member who has left are divided among the remaining members of the Board of Directors.

8. The elected Board of Directors runs the activities of the association and also carries out administrative functions if they have not been assigned to another organ of the association by the statutes or decision.

It mainly has the following functions:

- a) the execution of General Meeting's decisions
- b) the calling and preparation of General Meeting and conducting of the General Meeting by the chairperson or one of the representative chairpersons
- c) preparing the budget for every business year, account keeping, formulating annual reports
- d) the representation of the association in the international forum and among all dialog groups of the association

9. The Board of Directors

- can expand the Board by a consulting part: The elected Board can appoint up to 7 persons that support the elected Board in their tasks. Members of the expanded/consulting part can be members or non-members, that support the elected Board to fulfill the statutory purpose of the association.

Members of the expanded/consulting Board

- are not entitled to vote within the Board
- will be appointed for a maximum duration of 2 years. If necessary, the same persons can be appointed again.
- can call and recall advisory boards, e.g. medical advisory boards, to provide counsel about and to support its functions. Counsellors can be members or non-members.
- can call honorary members.
- can appoint a chief representative (e.g. in the function of a manager, association spokesperson etc.), on whom some functions of the Board of Directors can be transferred.

10. The elected Board of Directors will meet at least three times in a year for which the members of the Board of Directors should receive an invitation in writing at least 4 weeks before the date of the meeting. The Board of Directors is a quorum if at least 3 members are present at the meeting. The Board of Directors takes decisions with simple majority. In case of a draw the vote of the chairperson is considered twice. If for some reason one or more offices are unoccupied, all standard Board of Directors meetings are considered to have a quorum.

§ 8 Liability

The association's liability is limited to the extent of its assets. The liability of the office or function bearers (e.g. members of Board of Directors, auditors or employees etc.) does not extend to their private assets.

§ 9 Dissolution Of The Association

The association's dissolution can take place on the General Meeting's decision. The Board of Directors carries out the dissolution. With the dissolution of the association, all the association assets will be transferred to:

EORTC European Organisation for Research and Treatment of Cancer

In particular to the Research Group:

EORTC-STBGN (Soft Tissue and Bone Sarcoma Group) Research Group

Avenue Emmanuel Mounier 83/11, 1200 Brussels – Belgium

The assets should be only used for research projects and/or training/education of young physicians interested in Sarcomas.

These statutes and future amendments to them are available in German and English versions and can be downloaded at any time from www.sarcoma-patients.eu.

